

CARING FOR ONESELF: SOCIAL REPRESENTATIONS OF STROKE PATIENTS' FAMILY CAREGIVERS

Cuidado de si: representações sociais de cuidadores familiares de pacientes com AVC

Cuidado de sí mismos: representaciones sociales de los cuidadores de pacientes con familiares accidente cerebrovascular

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ABSTRACT

Objective: The study's main goal has been to investigate the social representations of stroke patients' family caregivers by focusing on self-care. **Methods:** It is a descriptive study, which used the theoretical approach of social representations. There were investigated 20 caregivers who attended two specialized clinics in Belém city, Pará State, Brazil. Data were collected through semi-structured interviews and processed by the inductive thematic analysis technique. **Results:** Self-care was represented by caregivers as difficult to combine to their activities of caring for the person suffering from stroke due to work overload, which generated stress and frustration. Some caregivers were able to transform this stress into a representation belonging to a complexity of their experience and the care reality. **Conclusion:** It was possible to access their social imagery and, consequently, the production of linked meanings as caregivers' actions, behaviors and cognitive components involved in the care reality.

Descriptors: Stroke, Caregivers, Social psychology, Nursing.

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RESUMO

Objetivo: Analisar as representações sociais de cuidadores familiares de pacientes acometidos por AVC, sobre o cuidado de si. **Método:** Estudo descritivo, no qual foi utilizado como aporte teórico as representações sociais. Foram investigados 20 cuidadores que frequentavam duas clínicas especializadas em Belém do Pará. Os dados foram coletados por meio de entrevistas semiestruturadas e organizados pela técnica de análise temática indutiva. **Resultados:** O cuidado de si foi representado pelos cuidadores como de difícil agregação às suas atividades de cuidar do adoecido pelo AVC devido à sobrecarga de trabalho, a qual gerou estresse e frustração. Alguns cuidadores conseguiram transformar esse estresse em uma representação pertencente a complexidade da sua vivência e da realidade do cuidado. **Conclusão:** Foi possível acessar o seu imaginário social e consequentemente a produção de significados atrelados às ações dos cuidadores, comportamentos e componentes cognitivos envolvidos na realidade do cuidar.

Descritores: Acidente vascular cerebral, Cuidadores, Psicologia social, Enfermagem.

RESUMEN

Objetivo: Analisar las representaciones sociales de los cuidadores de pacientes con accidente cerebrovascular de la familia en el auto cuidado. **Método:** Estudio descriptivo, que se utilizó como las representaciones sociales teóricas. Investigaron 20 cuidadores que asisten a dos clínicas especializadas en Belem. Los datos fueron recolectados a través de entrevistas semi-estructuradas y organizadas por la técnica de análisis temático inductivo. **Resultados:** El cuidado de sí estuvo representada por los cuidadores como difíciles de agregar sus actividades para atender a los enfermos por accidente cerebrovascular debido a la sobrecarga de trabajo, lo que causó el estrés y la frustración. Algunos cuidadores fueron capaces de convertir ese estrés en una representación que pertenece a la complejidad de su experiencia y la realidad cuidado. **Conclusión:** Fue posible acceder a los imaginarios sociales y por lo tanto la producción de significados vinculado las acciones de los cuidadores, el comportamiento y los componentes cognitivos implicados en la realidad de la atención.

Descriptor: Accidente cerebrovascular, Cuidadores, Psicología sociales, Enfermería.

INTRODUCTION

Stroke is a chronic-degenerative disease that has shown a reduction in the mortality rate in recent years due to medical and scientific advances in the field, but its prevalence has increased significantly as the population ages.¹ Worldwide, it is estimated that 15 million people are affected by stroke annually, of which 6.6 million are Americans.² In Brazil, 51.8 individuals die from the disease for each group of 100,000 citizens.³

Stroke patients suffer from motor and cognitive deficits that affect their ability to perform activities of daily living, such as performing simple household tasks, eating alone, bathing without assistance or remaining in extra-home practices. So, in the impossibility of taking care of themselves, the role of the caregiver is of fundamental

importance, since he is available to meet the biopsychosocial needs of the individual with a stroke, contributing to the promotion of his quality of life. Usually, the relative is the one who performs the functions of an informal caregiver.⁴

Such caregivers also face the consequences of stroke, as they often have physical, psychological, emotional, and social problems inherent to the care provision, in addition to being more susceptible to developing serious disease and are less likely to be involved in preventive measures of health. It is noteworthy that half of all caregivers have at least one chronic condition.⁵

Self-care, which is often disregarded by the family caregiver, constitutes a real issue, the consequences of which are multidimensional, in other words, they affect both the health of the caregiver and the person being cared for since it is first necessary to take care of oneself to have physical conditions, mental and social to care for others.⁶ Studies address that the main difficulties that lead caregivers to be careless about themselves are work overload, lack of family support, psycho-emotional problems, and low education.⁷⁻⁹ It is essential to know the social representation that caregivers have about the care offered, aiming to understand the subjective knowledge and the social context that permeate the process of caring for the other, since such representations are constructions created by common sense to assign meaning to their experience, based on communication and interaction with the environment in which they work.¹⁰

The addressed subject adds great value to scientific research due to the increasing need for caregivers to assist in the process of caring for patients who have suffered a stroke. Taking care of this caregiver, on the other hand, has still been little explored in the theoretical perspective of social representations and in the field of nursing science. This work intends to contribute to the advancement of investments in this field.

Faced with the problems experienced by caregivers in the search to implement care and take care of themselves, the following question was addressed: what is the social representation of stroke patients' family caregivers concerning self-care? To answer this question, this study meant to investigate the social representations of stroke patients' family caregivers by focusing on self-care.

METHODS

It is a descriptive study with a qualitative approach, which used the theory of social representations as theoretical support for the interpretation of results. Such theory develops under the reflection of how the relationship of man with his social environment occurs and from that, how he builds his knowledge about the world.¹¹

Among the fundamental processes for the formation of social representation are objectification and anchoring. Objectification consists of making real and giving shape to

the knowledge we have about the represented object, and thus make the palpable, concrete and visible. Anchoring is giving meaning to what is foreign to the group, it is making a connection between social representation and another that already exists.¹²

The locations chosen for the development of the research were the *Hospital Ophir Loyola (HOL)* and the *Unineuro* neurological clinic, both located in the metropolitan region of *Belém* city, *Pará* State, Brazil. The research participants consisted of 20 informal caregivers who accompanied their family members in ambulatory consultations. selected locations to develop this study. The choice of caregivers occurred through the convenience sampling method. The inclusion criteria used were as follows: being 18 years old or more, being the main caregiver. Caregivers who had been working for less than a year were excluded because they were recently involved in the development of direct care for stroke patients.

Data collection took place over six months in the caregivers' own homes, so that they were more comfortable giving their testimonies. Firstly, the selected health establishments were contacted at the time that caregivers arrived to accompany patients in ambulatory consultations. The research was presented and then the caregivers who agreed to participate after the presentation of the study, adherence to the inclusion and signature criteria and informed consent form, the data were collected at their homes.

During the data collection, a script was used containing the following guiding questions: Do you dedicate any moment of your day to take care of yourself while providing care to another person? How do you take care of yourself? What do you think about your activity as a caregiver? The interviews lasted an average of one hour and with the authorization of the participants, they were recorded on an MP4 device and transcribed for better decoding and data analysis. Data collection was interrupted as the study objectives were answered and new information was not added to the study.

The inductive thematic analysis technique was used for data arrangement.¹³ This was developed in six stages, as follows: 1) Data familiarization, which occurs through the transcription of data, active reading of the data and annotation of initial ideas; 2) Code generation, which occurs through the systematic coding of relevant data; 3) Search for themes, in which there is a grouping of codes in order to transform them into potential themes; 4) Continuous review of the themes, as new ones are elaborated, generating a thematic "map" of analysis; 5) Definition of the themes, through the ongoing analysis aiming at perfecting the specifics of each theme; 6) Production of the report through an explanatory interpretation. Through data analysis, inductively, it was possible to elaborate two themes that summarize the representations of caregivers: Caregivers consensual knowledge vis-à-vis providing care

to others; and, Self-care anchored in the art of taking care of others.

This work received approval from the ethics and research committee of the Health Sciences Institute from the *Universidade Federal do Pará* under the Legal Opinion No. 086/10. Aiming to identify the reports, fictitious names were applied to preserve the participants' anonymity. The participants were asked to sign the Informed Consent Form (ICF) prior to data collection. This research complied with the Resolution No. 466/2012 from the National Health Council.

RESULTS

Most family caregivers were female, representing 80% of the total participants. They were within the age group from 18 to 72 years old, with an average age from 38 to 48 years old (35%). 45% reported having completed high school, 80% were Catholics, 25% only worked in-home, 50% had their own income and 85% of caregivers lived with the family of the person affected by the stroke.

Caregivers consensual knowledge vis-à-vis providing care to others

The dependence generated by the stroke consequences is often the main justification reported by family caregivers for the lack of self-care. Nonetheless, in many cases, this meaning is anchored in the negative behavior of the caregiver in the face of the difficult task performed, making it difficult for the caregiver to identify self-care as an integral part of caring for the other, as shown below:

[...] I stopped studying, it compromised me, because I had to stop living my private life to take care of his health. In the wheelchair phase, I had to adapt to him, because I got stressed a lot, it made me go crazy. I would carry him up and down in the bathroom and my spine hurt a lot, I get as sick as he with this disease. (Sheila)

[...] I take care of others a lot and forget about myself. I was supposed to do some exams, but I couldn't because I have to stay with her; my self-care doesn't exist. I already got high blood pressure because of that, and I already had a heart attack, so, I think I'll also have a stroke because I'm sick just like her. (Maria)

Their subjectivities are linked to a concern with themselves, which is represented by a physical and psychological overload due to the integrality of their responsibility with a loved one. This lack of self-care results in the deprivation of self-techniques, the practice of which could guide them in the positive confrontation of their experience, reorienting their ideas, concepts, and praxis about the care provided and self-care.

The difficulty in taking care of yourself, in general, is

due to the lack of family support to deconcentrate the care required by the stroke consequences. It is common for only one caregiver to be in charge of meeting all the patient's needs, without receiving spontaneous help from other family members, ending up suppressing their own needs, as we can see in the reports below:

[...] My self-care is left for later, it's just me, so what can I do? (Lurdes)

[...] It is difficult to take care all the time and do everything by myself, I can do it, but on the other hand, I cannot take care of my health, it will never end. (Vitória)

[...] If I want to do something for myself, I have to pay someone, then you know, right, the money is short, and nobody helps out. (Marcelo)

In the participants' representations, since the care routine is considered a lonely activity, it is even more difficult to combine the activities of the caregiver with self-care. The presence of someone who offers help without expecting a financial return is represented as rare or even non-existent, contributing to the social isolation of this individual, denying himself the sharing of his experiences with his means of belonging, in addition to taking him to both physical and mental illness.

Self-care anchored in the art of taking care of others

When the caregiver goes through the process of objectifying the experienced situation, he is able to organize his observations and ideas about his universe of care, absorbing the meanings resulting from the classification of his current reality. Thus, when building an image about their reality, the caregiver crystallizes their representation, in other words, recognizes the situations that involve the care process, as we can identify in the participants' statements below:

Oh, I have got time, but to take care of someone like that, you know, my life is very stressed, we cannot take care of ourselves, our life is mainly to take care of the person. Sometimes stress strikes I don't know how to deal with it, I'm a calm person, but when stress strikes. Oh my God! (Rafaela)

I take care of everyone first, I only come later. I take care of everyone but me, I feel sick, but I feel good taking care of them, so I don't even miss taking care of me, my time is with them, so if they are okay, I am as well. I've already missed paying bills and going to the doctor because of my sister, but I do it, and I don't regret it. (Fernanda)

The complexity of taking care of a loved one with many physical limitations due to stroke is recognized, but there is

also well-being objectified in the simple fact of being useful and being able to provide quality of life to the person who needs care so much. Anchoring their daily lives in a positive representation allows the caregiver to assign meaning to their commitment, making this representation an integral part and rooted in their symbolic thought system, which influences their action.

On the other hand, the subjectivities of some caregivers are confronted from the image built on the other, in other words, the physical and mental exhaustion generated by the burden of care can corroborate the objectification that life can be better in the absence of being cared for and of the entire symbolic universe it carries. Such representation is anchored in the reports below:

[...] I think when my father dies it will be a relief, both for him and for me, I know that sometimes it is a sin, but I think this way. (Karina)

[...] If she didn't have it, things would be better, I would go back to work and attend my appointments, sell my cosmetics, and have more money to buy my things. (Raísa)

In the context of social representations, all thought is produced based on the identity of the individual, his culture, and the social environment in which he is inserted. Accordingly, a representation is not built by means of an isolated manifestation but is based on concepts elaborated from common sense and its subjective relations.

Considering the concept of self-care, the time dedicated to the other is not the cause of the lack of self-care, but the lack of self-awareness. In other words, when caregivers are more concerned with how to take care of themselves only when they no longer need to take care of the loved one, they end up forgetting who they are. If they knew who they are, they would know the art of being better people for themselves and for others. Hence, caregivers will only be able to take care of themselves when they really know themselves.

DISCUSSION

Herein, self-care was represented by all participants as difficult to combine to their activities as caregivers, in which they pointed out the stroke patient and the environment in which they live as the main contributors to the stress generated by not taking care of themselves.

The predominance of the female sex working as a caregiver added to the average age of the participants and the coexistence with the person affected by stroke are the factors found that most collaborate for work overload and neglect in self-care since the care provided by women are

represented in many cultures, mainly by wives and mothers, often from the home.¹⁴

Another essential factor for the caregiver's workload is the need for care of the loved one, which will depend on the intensity of the stroke consequences. The representations of the participants in this study are anchored in almost total dependence on the patient, revealing that this is the main reason for the frustration and stress of caregivers for not being able to take care of themselves. Such feelings were manifested, in particular, in the speeches of the participants Lurdes, Vitória, and Marcelo.

In Rafaela's report, the representation of stress was evidenced as a compromising factor in the care provided, but self-care is also hampered by stress. On the other hand, practicing self-care can avoid stress and help the caregiver to better manage their routine and maintain their social relationships. By employing the techniques of oneself, the caregiver will be using procedures to obtain his identity while seeking to reach a certain end, which in this case consists of emotional balance, according to the relations of self-control or self-knowledge.¹⁵

Hence, the self-knowledge is understood as an end in itself, something to be sought, and not a consequence of taking care of oneself. By taking this concept as the basis for her representational universe, it is possible that caregiver Rafaela transforms this stress, classified as threatening and disturbing, into a representation pertaining to the complexity of her experience and thus learning to deal with stress influencing her relationship with caring since this relationship has a constructive, creative, autonomous character, which allows the interpretation of the object and expression of the subject.¹⁶

The consequences of not taking care of themselves can generate different impacts on the health of caregivers,⁹ a fact well represented in the speech of participant Maria, who bases her health issues in her caregiver activities, which were considered extremely costly, and did not show any prospect of taking care of herself, despite recognizing herself as a sick person. Consequently, the concrete content of Maria's representational thought bears her mark, as a subject, and of her attitudes towards the experience of caring for an individual with many stroke consequences.¹⁷

In this respect, the participant's world view involves her social imaginary and the position she occupies in relation to others, in which this relationship is not the only objective, but also subjective, where there is a confrontation between themselves and, at the same time, with the image you created of the other. This is because through the representations

of caregivers there is the construction of certain social consensus, on which their practices are transformed, sometimes giving rise to new representations.¹⁸

These physical and psychological problems of caregivers aim at a lesser capacity to offer quality care and at the same time increase their morbidity.¹⁹ Then, it is necessary that caregivers, especially, like Maria, start to represent the care of themselves as a feeling that one has about oneself from the perceived lack, as well as understanding that the master is the one who takes care of the subject's self-care.²⁰

The low financial income is anchored by some participants as a factor that contributes to the lack of quality of life and, consequently, the lack of self-care. Raísa's statement addresses that her representation is based on the psychological and social elaboration of the reality experienced before the stroke, in other words, the transformation that occurred in her routine after becoming a caregiver made her wish that the disease did not integrate her symbolic universe. Hence, it is possible to identify that the participant anchors the unknown in already existing representations.

Marcelo brings in his statement the financial difficulty to pay a secondary caregiver so that he can be absent from his responsibility as a caregiver to take care of himself since another member of the family is not willing to help spontaneously in such activity. Its representation incorporates socio-cognitive mechanisms that add positive thinking around its function and conduct that expresses balance.²¹ Therefore, Marcelo's representation exercises an influence on the construction of common-sense knowledge.

Given this framework, spiritual subjectivity can be a way of caring for oneself, which is only objectified in Rafaela's account when she, when she says she doesn't know how to deal with stress, mentions at the end of her speech the phrase "Oh my God", which reveals the presence of a probable spiritual belief, nevertheless, it might not be rooted in her representational system. It is possible that the participant believes in God, but the representation of her report does not express an outward spirituality, which influences their behavior in relation to their experience as a caregiver.

Here, it is underlined the importance of carrying out more studies that use the framework of social representations, targeting to value the approach of understanding common sense and, consequently, to have a better dynamic approach between nurses, patients, family caregivers, and their respective social groups.

Study limitations

As a limiting factor of the study, it was identified that if the research was performed with a group of predominantly male caregivers, different representations would certainly come about. Therefore, as in this study, many others have a predominance of women as caregivers. Such fact calls for further investigation addressing self-care under the social representation of stroke patients' male caregivers.

Contributions to Nursing

Nursing, as a science and profession, needs to be always conducting its care to the patient and family dyad, aiming to consider that each person, from his subjectivity, will mean taking care of himself in different ways, but such care is for everyone. So, as the nurse takes care of others, such professional also reveals to the family caregiver the possibilities for establishing a relationship of experiences both in the care of the other and of himself.

CONCLUSION

Through this research it was possible to understand that the social representations of family caregivers were represented by the lack of time to take care of themselves, in their health problems resulting from the exhaustive and lonely task of caring for a loved one with many physical limitations generated by the stroke, and in the meanings attributed by each participant to the caregiver experience. Almost all speeches were fraught with physical and mental exhaustion, sadness for giving up certain personal activities, and frustration for not being able to effectively take care of themselves.

By analyzing the social representations of stroke patients' family caregivers, it was possible to access their social imaginary and consequently the production of meanings linked to their actions, behaviors and cognitive components involved in the reality of care and in the formation of their social identity, which is related to directly to their collective practices, in other words, to common sense that caregivers share within a group. Then, such representations can provide support for the registered nurse to elaborate, through interaction with others and social communication, care strategies towards both the family caregiver and the stroke patient, anchoring their practices in the subjectivities and psychosocial limitations of each caregiver, helping them to deal with the challenges of the familiarization process of specific situations concerning the care routine.

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